

Date of Hearing: April 20, 1999

ASSEMBLY COMMITTEE ON JUDICIARY  
Sheila James Kuehl, Chair  
AB 1592 (Aroner) – As Amended: April 15, 1999

SUBJECT: THE DEATH WITH DIGNITY ACT

KEY ISSUES:

- 1) SHOULD CALIFORNIA ENACT THE DEATH WITH DIGNITY ACT, MODELED AFTER A SIMILAR TWO-YEAR-OLD OREGON MEASURE, WHICH WOULD AUTHORIZE COMPETENT ADULTS SUFFERING FROM A TERMINAL ILLNESS TO HAVE THE FREEDOM TO SEEK MEDICATION TO HASTEN THE END OF THEIR LIVES IN A HUMANE AND DIGNIFIED MANNER?
- 2) DOES THE DEATH WITH DIGNITY ACT CONTAIN APPROPRIATE AND SUFFICIENT SAFEGUARDS TO ENSURE THAT ONLY THOSE COMPETENT, TERMINALLY ILL INDIVIDUALS WHO HAVE FREELY MADE REPEATED REQUESTS FOR MEDICATION TO HASTEN THE END OF THEIR LIVES IN A HUMANE AND DIGNIFIED MANNER, MAY UTILIZE THIS OPTION?
- 3) IS THIS BILL FUNDAMENTALLY DIFFERENT FROM THE TYPE OF ACTIVE EUTHANASIA THAT RESULTED IN DR. JACK KEVORKIAN'S RECENT CONVICTION?
- 4) IS IT PREMATURE TO ENACT THE DEATH WITH DIGNITY ACT GIVEN THE CURRENT LACK OF ADEQUATE ACCESS TO HEALTH CARE, INCLUDING HOSPICE AND COMFORT CARE, FOR MANY CALIFORNIANS?

SUMMARY: Enacts the Death with Dignity Act, which would authorize competent adults who have been determined by two physicians to be suffering from a terminal disease to make a request for medication to hasten the end of their lives in a humane and dignified manner. Specifically, this bill:

- 1) States the intent of the Legislature with respect to this Act as follows:
  - a) The Legislature believes that dying patients should have choices throughout the continuum of palliative care and that much must be done to improve access to hospice care and pain management. The Legislature finds that medical studies have shown between 5 and 10 percent of dying patients experience severe pain and suffering that cannot be palliated by the best hospice or comfort care. The Legislature finds that in response to the Death with Dignity Act in the State of Oregon, that the referrals to hospice increased significantly. In addition, doctors significantly increased the use of morphine and other strong pain medications, thus improving the end of life care for more dying patients.
  - b) It is the intent of the Legislature that the choice of physician-assisted dying, as defined in this chapter, be viewed as an end-of-life option for dying patients.

- c) It is the intent of the Legislature that the provisions of this chapter be strictly construed and not expanded in any manner. The restrictions and safeguards of this chapter are based on the intent of the Legislature that balances the personal and autonomous choice of dying patients regarding the time and manner of their death and the Legislature's goal of providing safeguards to ensure that there are no instances of coerced, unwanted, or early death by a vulnerable dying patient.
  - d) It is the intent of the Legislature that a disability or age alone is not reason for a patient to be eligible for the provisions of this Act. Any individual with a disability or elderly person, and any physician who is the attending physician to these individuals, must strictly comply with all of the provisions of this chapter. Strict and rigorous attention must be evidenced in distinguishing chronic conditions, which are not eligible conditions under this chapter, and terminal illnesses, which are eligible, as described in this chapter. (Proposed Health and Safety Code Section 7195, p. 3, lines 5-40 & p. 4, lines 1-2. All further statutory references are to this code unless otherwise noted.)
- 2) Authorizes an adult who is competent, is a resident of California, has been determined by the attending physician and a consulting physician to be suffering from a terminal disease, and who has voluntarily expressed the wish to hasten the end of his or her life, to make a written request for medication for the purpose of hastening the end of his or her life in a humane and dignified manner, in accordance with strict procedural requirements. (Proposed Section 7195.3, p. 5, lines 28-35.)
  - 3) Provides that nothing in the Act shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing, or active euthanasia. It also provides that actions taken in accordance with the Act shall not, for any purpose, constitute suicide, assisted suicide, mercy killing, or homicide under the law. (Proposed Section 7197.7, p. 10, lines 22-27.)
  - 4) Provides that no person shall receive a prescription for medication to hasten the end of his or her life in a humane and dignified manner unless all of the following conditions are met:
    - a) The patient must be terminally ill, as determined by at least the attending physician and a consulting physician. (Proposed Section 7195.3, p. 5, lines 28-35.)
    - b) The patient has made an informed decision, which must be verified by the attending physician. (Proposed Section 7196.3, p. 7, lines 37-40 & p. 8, lines 1-4.)
    - c) The patient has made an oral request and a written request, and reiterated the oral request to his or her attending physician, not less than 15 days after making the initial oral request. At the time of the second oral request, the attending physician shall offer the patient the opportunity to rescind the request. (Proposed Section 7196.5, p. 8, lines 10-18.)
    - d) Not less than 15 days shall elapse between the patient's initial oral request and the writing of the prescription. Not less than 48 hours shall elapse between the patient's written request and the writing of the prescription. (Proposed Section 7196.7, p. 8, lines 25-29.)

- e) The attending physician must ask the patient to notify the patient's next of kin of his or her request for medication under the Act. However, a patient who declines or is unable to notify next of kin shall not have his or her request denied solely for that reason. (Proposed Section 7196.4, p. 8, lines 5-9.)
- 5) Requires the patient's attending physician to do all of the following:
- a) Make the initial determination of whether the patient has a terminal disease, is capable (as defined in #10b below), and has made the request voluntarily.
  - b) Inform the patient of all of the following: his or her medical diagnosis and prognosis; the potential risk associated with taking the medication to be prescribed; the probable result of taking the medication to be prescribed; and the feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.
  - c) Refer the patient who has requested medication under the Act to a consulting physician for a second opinion of the diagnosis, and for a separate and independent determination that the patient is capable, acting voluntarily, and is making an informed decision.
  - d) Refer the patient for counseling, if appropriate (as specified in #7 below).
  - e) Request that the patient notify next of kin.
  - f) Inform the patient that he or she has an opportunity to rescind the request at any time and in any manner, and offer the patient an opportunity to rescind at the end of the required 15-day waiting period.
  - g) Verify, immediately prior to writing the prescription for medication, that the patient is making an informed decision.
  - h) Document or file all of the following in the patient's medical record: (i) all oral and written requests by a patient for medication to hasten the end of his or her life in a humane and dignified manner; (ii) both the attending physician's and consulting physician's diagnoses and prognoses, and their determinations that the patient is capable, acting voluntarily, and has made an informed decision; (iii) a report of the outcome and determinations made during counseling, if performed; (iv) the attending physician's offer to the patient to rescind his or her request at the time of the patient's second oral request; (v) the attending physician's discussion with the patient of feasible alternatives including, but not limited to, hospice care, comfort care and pain control; and, (vi) a note by the attending physician indicating that all of the requirements of the Act have been met and indicating the steps taken to carry out the request, including a notation of the medication prescribed.
  - i) Ensure that all appropriate steps are carried out in accordance with the Act prior to writing a prescription for medication to enable a qualified patient to hasten the end of his or her life in a humane and dignified manner. (Proposed Section 7196, p. 6, lines 24-39 & p. 7, lines 1-19;

Section 7196.8, p. 8, lines 30-40 & p. 9, lines 1-14.)

- 6) Requires a consulting physician to examine the patient and his or her relevant medical records and confirm, in writing, the attending physician's diagnosis that the patient is suffering from a terminal disease, and verify that the patient is capable, is acting voluntarily, and has made an informed decision. (Proposed Section 7196.1, p. 7, lines 20-26.)
- 7) Provides that if in the opinion of the attending physician, or the consulting physician, a patient may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment, either physician shall offer the patient counseling. It also provides that no medication to hasten the end of a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder, or from depression causing impaired judgment. (Proposed Section 7196.2, p. 7, lines 27-36.)
- 8) Provides that a patient may rescind his or her request at any time and in any manner without regard to his or her mental state. It also provides that no prescription for medication under the Act may be written without the attending physician offering the qualified patient an opportunity to rescind the request. (Proposed Section 7196.6, p. 8, lines 19-24.)
- 9) Provides that a valid request for medication shall substantially conform with the form prescribed in the Act, and shall be signed and dated by the patient and witnessed by at least two individuals who, in the presence of the patient, attest that to the best of their knowledge and belief the patient is capable, acting voluntarily, and is not being coerced to sign the request. It also provides that one of the witnesses shall not be any of the following: (a) a relative of the patient by blood, marriage, or adoption; (b) a person who at the time of the request would be entitled to any portion of the estate of the qualified patient upon death under any will or by operation of law; (c) an owner, operator, or employee of a health care facility where the qualified patient is receiving medical treatment or is a resident. The patient's attending physician at the time of the request is also disqualified from serving as a witness. It further provides that if the patient is a patient in a long-term health care facility at the time the written request is made, one of the witnesses shall be an individual designated by the facility and having qualifications specified in regulations adopted by the State Department of Health Services. (Proposed Section 7195.5, p. 5, lines 36-40 & p. 6, lines 1-20.)
- 10) Defines, for the purposes of the Act, various terms at Section 7195.1, pages 4-5, including:
  - a) "Adult" means an individual who is 18 years of age or older.
  - b) "Capable" means that in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, a patient has the ability to make and communicate health care decisions to health care providers, including communications through persons familiar with the patient's manner of communicating if those persons are available. Incapable means not capable, as defined.

- c) "Informed decision" means a decision, made by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts, and is made after being fully informed by the attending physician of all of the following: (i) his or her medial diagnosis and prognosis; (ii) the potential risk associated with taking the medication to be prescribed; (iii) the probable result of taking the medication to be prescribed; and, (iv) the feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.
  - d) "Patient" means a person who is under the care of a physician.
  - e) "Physician" means a doctor of medicine or osteopathy licensed to practice medicine by the Medical Board of California.
  - f) "Qualified patient" means a capable adult who is a resident of California and has satisfied the requirements of the Act in order to obtain a prescription for medication to end his or her life in a humane and dignified manner.
  - g) "Resident" means a person who has lived in a principal place of residence in the State of California for six months or more.
  - h) "Terminal disease," means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.
- 11) Provides that only requests made by California residents under the Act shall be granted. (Proposed Section 7196.9, p. 9, lines 15-16.)
- 12) Provides that no provision in a contract, will, or other agreement shall be valid to the extent it would affect whether a person may make or rescind a request for medication to end his or her life more quickly in a humane and dignified manner. (Proposed Section 7197.3(a), p. 9, lines 28-32.)
- 13) Provides that no health care service plan contract, nor any provision of a policy of disability insurance or a health benefit plan contract that provides coverage for hospital, medical, or surgical expenses shall be conditioned or affected by the making or rescinding of a request by a person for medication to end his or her life in a humane and dignified manner. Any such contract or policy provision shall be invalid. (Proposed Section 7197.3(c), (d), p. 9, lines 38-40 & p. 10, lines 1-11.)
- 14) Prohibits the sale, procurement, or issuance of any life, health, or accident insurance or annuity policy, or the rate charged for any policy, from being conditioned upon or affected by a request made under the Act. (Proposed Section 7197.5, p. 10, lines 12-21.)
- 15) Provides immunity from civil or criminal liability or professional disciplinary action for participating in good faith compliance with the Act. (Proposed Section 7198(a), p. 10, lines 31-37.)
- 16) Requires the State Department of Health Services to adopt regulations regarding requirements for the collection of information to determine the use of and compliance with the Act. It also requires the

department to annually review a sample of certain records and make available to the public an annual statistical report regarding the information collected. (Proposed Section 7197.1., p. 9, lines 17-27.)

- 17) Provides that no health care provider shall be under any duty to participate in providing medication to a qualified patient if that health care provider is unable or unwilling to carry out a patient's request. (Section 7198(d), p. 11, lines 9-18.)
- 18) Provides that anyone who coerces or exerts undue influence on a patient to request medication shall be guilty of a felony. (Section 7198.5(b), p. 11, lines 24-27.)
- 19) Provides that anyone who alters or forges a request without authorization of the patient or who destroys or conceals a rescission of a request shall be guilty of a felony. (Section 7198.5(a), p. 11, lines 19-23)
- 20) Provides that nothing in the Act limits liability for civil damages resulting from negligent conduct or intentional misconduct by any person. (Section 7198.5(c), p. 11, lines 28-30.)

#### EXISTING LAW:

- 1) Provides that a competent adult has a fundamental right to accept or reject medical treatment, including the right to withdraw or withhold life-sustaining treatment that may cause or hasten the individual's death. (See e.g., Cruzan v. Director, Missouri Dept. of Health (1990) 497 U.S. 261; Thor v. Superior Court (1993) 5 Cal.4<sup>th</sup> 725; Cobbs v. Grant (1970) 8 Cal.3d 229.)
- 2) Authorizes, under the Natural Death Act, an adult of sound mind to execute a declaration governing the withholding or withdrawal of life sustaining treatment. (Section 7185 et seq.)
- 3) Authorizes an adult of sound mind to appoint an attorney-in-fact (agent) to make health care decisions for that individual in the event of his or her incapacity pursuant to a durable power of attorney for health care. (Probate Code Section 4600 et seq.)
- 4) Provides that every person who deliberately aids or advises, or encourages another to commit suicide, is guilty of a felony. (Penal Code Section 401.)

#### FISCAL EFFECT: Unknown

COMMENTS: Seldom have more legally important, and controversial issues come before this Committee. Although similar legislation was introduced in 1995, it was never heard by any committee. This Committee, therefore, is addressing this challenging and momentous legal and social issue as one of "first impression" in this state. Its determination will clearly strike important chords, not just in California but around the country.

Introduction. The Death with Dignity Act proposed in this legislation permits a physician to respond to repeated requests of a competent, terminally ill patient by writing a prescription for medication which, if

taken by the patient, will hasten the end of his or her life in an arguably more humane and dignified manner. This legislation forces us to grapple with some of the most difficult and troublesome questions we can ever face, such as the meaning and value of life and death, which is intertwined with our notions of liberty and personal autonomy, as well as how we as a society should protect these interests. Numerous writings have addressed each of these subjects, and it is impossible to adequately cover them all here. Rather, it is the hope of the writers of this analysis that the following information will provide at least some guidance to the Committee members and others as they struggle with the profound public policy questions presented by this legislation.

Overview of Analysis. This analysis begins with a statement of purpose by the author, followed by a brief description of the recent conviction of Dr. Kevorkian in Michigan and the legal backdrop to the bill. It will then turn to the legislative backdrop for the bill, and a brief review of the limited empirical evidence being developed in the few areas where physician-assisted dying is being openly practiced. The analysis then turns to the social and medical issues that help form the background of the proposal. Finally, a summary of the principal arguments of supporters and opponents is included.

Terminology. In this analysis, we use the term "physician-assisted dying" rather than "physician-assisted suicide" to describe this legislative proposal. The law does not classify the death of a patient that results from the granting of his or her wish to decline or discontinue treatment as a "suicide." Nor does the law label the acts of those who help the patient carry out that wish, whether by physically disconnecting the respirator or by removing an intravenous tube, as assistance in suicide. Accordingly, we use the term "physician-assisted dying" because it appears to more accurately reflect the strictly circumscribed actions of patients and doctors that appear to be authorized under the bill.

Author's Statement. The author states she introduced the Death with Dignity Act because she believes the time has come to begin a sincere societal discussion of how we treat dying patients. According to the author, our history of treatment for dying patients has not always been positive. Our medical systems tend to put resources into keeping patients alive at all costs, even when that is not the choice of the patient. The author believes the range of care for dying patients must include choices for those relatively few whose suffering is extreme and cannot be palliated despite our best efforts.

The author is strongly opposed to suicide. She states that the bill is narrowly tailored to allow physician-assisted dying only for terminally ill, competent patients. She notes she does not, and the bill does not, allow or condone in any way the suicide of someone who is severely depressed, not able to make a competent decision, and not immutably at the end of his or her life. Despite the advances in medical technology which have increased the ability to save and prolong life, the author believes that each person must have the personal freedom and ability to choose his or her final moments based on individual moral, ethical and religious beliefs.

The author states that doctors who assist such patients should not be subject to criminal sanctions for engaging in a compassionate act. "Our systems of health care have produced a modern dilemma: Under current California law, terminally ill patients who want to die may request that the medical system not treat them further but may not request medication to hasten their death. [This] bill simply provides compassionate medical assistance by a willing physician to dying patients who choose a humane and dignified death."

Bill's Treatment Of Recent Kevorkian Case. The infamous Dr. Jack Kevorkian, a former pathologist from the State of Michigan, is widely reported as having assisted over 100 people with terminal illnesses in carrying out their wishes to end their suffering. On September 17, 1998, Kevorkian gave 52-year-old Thomas Youk, a victim of Lou Gehrig's disease, three injections: one to put him to sleep; one to stop his breathing; and one to stop his heart. As virtually everyone is aware, we know this not just because Kevorkian freely admits it, but also because he videotaped the entire process and turned it over to the CBS television show "60 Minutes" so the whole nation could watch. Last month, Dr. Kevorkian was convicted of second degree murder for the killing of Mr. Youk, and he was sentenced to state prison for 10-25 years.

A similar fate would face any would-be "Dr. Kevorkian" in California under this bill. AB 1592 makes clear that "[n]othing in this chapter shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing, or active euthanasia." (Proposed Section 7197.7, p. 10, lines 22-25.) Moreover, the bill specifically provides that the penalties in the Act "do not preclude criminal penalties applicable under other law for conduct that is inconsistent with this chapter." (Proposed Section 7198.5(d), p. 11, lines 31-33.) In addition, any person who coerces or exerts undue influence on a patient to request medication for the purpose of ending the patient's life, or who willfully alters or forges such a request with the intent or effect of causing the patient's death, is guilty of a felony. (Proposed Section 7198.5(a), (b), p. 11, lines 19-27.)

#### Legal Backdrop:

The "Cruzan" Case. In Cruzan v. Director, Missouri Dept. of Health (1990) 497 U.S. 261, the U.S. Supreme Court considered for the first time whether or not there is a constitutionally-protected, due process liberty interest in terminating unwanted medical treatment. The Court held that "[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions." (Cruzan, 497 U.S. at 278.) In her concurrence, Justice O'Connor explained that the majority opinion held (implicitly or otherwise) that a liberty interest in refusing medical treatment extends to all types of medical treatment from dialysis or artificial respirators to the provision of food and water by tube or other artificial means. As Justice O'Connor said: "I agree that a protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions, and that the refusal of artificial delivery of food and water is encompassed in that liberty interest." (Cruzan, 497 U.S. at 287 (O'Connor, J., concurring).)

The ultimate question before the Cruzan Court was whether or not the State of Missouri could constitutionally require clear and convincing evidence of a comatose patient's previously stated wish not be kept alive by artificial provision of food and water, which the Court answered in the affirmative. As Chief Justice Rehnquist said in the majority opinion:

"The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements. It cannot be disputed that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment." (Id., at 281.)



Justice O'Connor further concluded that under the majority's opinion, "[r]equiring a competent adult to endure such procedures against her will burdens the patient's liberty, dignity, and freedom to determine the course of her own treatment." (*Id.*, at 289 (O'Connor, J., concurring).)

Overview of Federal "Assisted-Suicide" Cases. In January 1994, four physicians, along with three terminally ill patients and Compassion in Dying, a nonprofit organization that counsels people considering physician-assisted dying, sued in the federal district court seeking a declaration that the State of Washington's statute which makes assisting a suicide a crime was unconstitutional. (*Compassion in Dying v. Washington* (WD Wash. 1994) 850 F.Supp. 1454.) The plaintiffs asserted the existence of a liberty interest protected by the Fourteenth Amendment which extends to a personal choice by a mentally competent, terminally ill adult to commit physician-assisted suicide." (*Id.*, at 1459.) On May 3, 1994, the District Court agreed and concluded that Washington's assisted-suicide ban is unconstitutional on both due process and equal protection grounds. (*Id.*, at 1465-1466.)

In March 1995, a panel of the Court of Appeals for the Ninth Circuit reversed the lower court's ruling in a 2-1 decision. (*Compassion in Dying v. Washington* (9<sup>th</sup> Cir. 1995) 49 F.3d 586.) The Ninth Circuit reheard the case *en banc*, reversed the panel decision, and affirmed the District Court. (*Compassion in Dying v. Washington* (1996) 79 F.3d 790, 798.) Like the District Court, the *en banc* Court of Appeals concluded that "the Constitution encompasses a due process liberty interest in controlling the time and manner of one's death – that there is, in short, a constitutionally-recognized 'right-to-die.'" (*Id.*, at 816.) After "[w]eighing and then balancing" this interest against Washington's various interests, the court held that the State's assisted-suicide ban was unconstitutional "as applied to terminally ill competent adults who wish to hasten their deaths with medication prescribed by their physicians." (*Id.*, at 836, 837.) The Ninth Circuit did not reach the District Court's equal protection holding.

During this same time frame, a similar case was brought in New York State by Dr. Timothy Quill, other physicians and terminally ill patients against the State of New York, challenging its assisted-suicide ban. (*Quill v. Koppel* (SDNY 1994) 870 F.Supp. 78.) In that case, plaintiffs argued that because New York permits a competent person to refuse life-sustaining medical treatment, and because refusal of such treatment is "essentially the same thing" as physician-assisted suicide, New York's assisted-suicide ban violates the Equal Protection Clause. The District Court disagreed (*Id.*, at 84-85), but it was reversed by the Second Circuit Court of Appeals. (80 F.3d 716 (1996).)

Both Washington and New York appealed to the U.S. Supreme Court, which agreed to review the two cases. Scores of *amicus* (friend-of-the-court) briefs were submitted by groups on both sides of the issue. On June 26, 1997, the Supreme Court issued companion decisions in both cases, ruling 9-0 that the Washington and New York bans on assisted-suicide do not offend either the due process clause (*Washington v. Glucksberg* (1997) 117 S.Ct. 2259) or equal protection clause of the *federal* constitution. (*Vacco v. Quill* (1997) 117 S.Ct. 2294.)

Supreme Court Leaves Matter of Physician-Assisted Dying to the States. Although the *Washington v. Glucksberg* and *Vacco v. Quill* decisions declined to recognize a constitutional right of terminally ill patients to receive medical help in hastening their deaths, the Supreme Court in those cases has, importantly for consideration of this bill, expressly allowed each state to decide whether to legalize the

intervention. Chief Justice Rehnquist, writing for the Court, said: "Throughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society." (Washington v. Glucksberg, *supra*, 117 S.Ct. at 2275.) Justice O'Connor wrote that "[s]tates are presently undertaking extensive and serious evaluation of physician assisted suicide and other related issues. ... In such circumstances, 'the ... challenging task of crafting appropriate procedures for safeguarding ... liberty interests is entrusted to the "laboratory" of the States ... in the first instance.'" (*Id.*, at 2303 (O'Connor, J., concurring)(citations omitted).) Similarly, Justice Souter wrote, "Legislatures ... have superior opportunities to obtain the facts necessary for a judgment about the present controversy. Not only do they have more flexible mechanisms for fact-finding than the Judiciary, but their mechanisms include the power to experiment, moving forward and pulling back as facts emerge within their own jurisdictions... ." (*Id.*, at 2293, (Souter, J., concurring).)

Overview of California Case Law. The California courts have not yet faced the question of whether this state's ban on assisted suicide violates the constitutional right of a competent, terminally ill resident to physician-assisted dying. However, it is well-established that a competent, informed adult has a right protected by the common law of this state, and by this state's statutes as well as our explicit constitutional right to privacy, to give or withhold consent to medical treatment, even in cases where the refusal or withdrawal of treatment may cause or hasten the individual's death. (See e.g., Thor v. Superior Court (1993) 5 Cal.4<sup>th</sup> 725; Bouvia v. Superior Court (1986) 179 Cal.App.3d 1127; Bartling v. Superior Court (1984) 163 Cal.App.3d 186; Cobbs v. Grant (1972) 8 Cal.3d 229; see also Health and Safety Code Section 7185 *et seq.*) The California courts have consistently based their decisions in this area on the individual's fundamental right to self-determination. In the Thor decision, the California Supreme Court cited the following oft-quoted passages in support of its decision upholding the right of patients to control their own medical treatment:

More than a century ago, the United States Supreme Court declared, "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to possession and control of his own person, free from all restraint or interference by others, unless by clear and unquestionable authority of law. ... 'The right of one's person may be said to be a right of complete immunity: to be let alone.'" (Union Pacific Railway Co. v. Botsford (1891) 141 U.S. 250, 251.) Speaking for the New York Court of Appeals, Justice Benjamin Cardozo echoed this precept of personal autonomy in observing, 'Every human being of adult years and sound mind has a right to determine what shall be done with his own body....' (Schloendorff v. Society of New York Hospital (1914) 211 N.Y. 1255.) And over two decades ago, Justice Mosk reiterated the same principle for this court: "[A] person of adult years and in sound mind has the right, in the exercise of control over his body, to determine whether or not to submit to lawful medical treatment." (Cobbs v. Grant (1972) 8 Cal.3d 229, 242.)

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It is antithetical to our scheme of ordered liberty and to our respect for the autonomy of the individual for the State to make decisions regarding the individual's quality of life. It is for the patient to decide such issues. (Citations omitted.) ... The fact that an individual's decision to forgo medical intervention may cause or hasten death does not qualify the right to make that decision in the first instance. (Bouvia, *supra*, 179 Cal.App.3d at pp. 1143, 1144; In the Matter of Farrell, *supra*, 108 N.J. 335.)

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Since death is the natural conclusion of all life, the precise moment may be less critical than the quality of time preceding it. Especially when the prognosis for full recovery from serious illness or incapacitation is dim, the relative balance of benefit and burden must lie within the patient's exclusive estimation: "That personal weighing of values is the essence of self-determination." (*In re Gardner*, *supra*, 534 A.2d at 955; *Conservatorship of Drabick* (1988) 200 Cal.App.3d 185, 208; *Barber*, *supra*, 147 Cal.App.3d at 1019; *Rasmussen v. Fleming*, 154 Ariz. 207.)

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[T]he state has not embraced an unqualified or undifferentiated policy of preserving life at the expense of personal autonomy. (*Cruzan*, *supra*, 497 U.S. at 314, fn. 15 (dis. opn. of Brennan, J.) ... No state interest is compromised by allowing [an individual] to experience a dignified death rather than an excruciatingly painful life. (*Donaldson v. Lungren*, *supra*, 2 Cal.App.4th at p. 1622.)

(*Thor v. Superior Court*, *supra*, 5 Cal.4th at 731-741.)

Given the explicit right to privacy in our state constitution (Cal. Const., Art. I, Sec. 1; see *American Academy of Pediatrics v. Lungren* (1977) 16 Cal.4th 307, 326) and the long history of strong protection of the fundamental autonomy rights of individuals to determine the course of their own medical treatment, our state courts may well recognize, on independent state constitutional grounds, the right of a competent, terminally ill adult to physician-assisted dying as a logical extension of the right to refuse life-sustaining treatment that will hasten death. However, as noted above, it does not appear necessary to reach this question since the U.S. Supreme Court carefully and unequivocally stated its preference that each state decide on its own whether or not to enact physician-assisted dying legislation.

Legislative Backdrop. In 1995, two identical measures - AB 1080 (Martinez) and AB 1310 (Mazzoni) – were introduced that were also modeled after the Oregon Death with Dignity Act. Neither measure was brought up for a hearing at that time in this Committee.

Proposition 161, which would have allowed either the administration of lethal medications by a physician (i.e., active euthanasia) or self-administration of lethal medications by a patient, was rejected by the California voters by a 46% to 54% margin at the General Election held November 3, 1992. However, the issues presented in Proposition 161 were much different than those presented here. As noted above, AB 1592 only permits the writing of a prescription for medication by the physician, which the patient may or may not take to hasten death. AB 1592 also contains greatly expanded safeguards not presented to the voters in Proposition 161 seven years ago.

Empirical Evidence. There are only two places in the world where physician aid in dying has been studied: Oregon and the Netherlands. Below is a very brief review of some of the empirical evidence regarding the experiences in these two locations.

Oregon's Death with Dignity Act: The First Year's Experience. As noted above, this bill is virtually identical to Oregon's Death with Dignity Act. Oregon's act, a citizen's initiative (Measure 16), was first passed by Oregon voters in November 1994 by a margin of 51% in favor to 49% opposed. Immediate implementation of the act was delayed by a legal injunction, which was lifted by the Ninth Circuit Court of Appeals on October 27, 1997 (*Lee v. State of Oregon*, 107 F.3d 1382), and physician-assisted dying

became a legal option for terminally ill patients in Oregon beginning late 1997. In November 1997, Measure 51 was placed on the general election ballot that asked Oregon voters to repeal the Death with Dignity Act. Voters chose to retain the act by a margin of 60% to 40%.

Currently, Oregon is the only place in the world where physician-assisted dying is legal. The Oregon Death with Dignity Act (like this bill) allows terminally ill state residents to receive prescriptions for self-administered lethal medications from their physicians. However, it is important to note that neither the Oregon act nor this bill permits euthanasia, in which a physician or other person directly administers a medication to a patient in order to end his or her life.

Like the proposed legislation, the Oregon act requires its state health department to collect information about the patients and physicians who participate in legal physician-assisted dying, and publish an annual statistical report. On February 18, 1999, the Oregon Health Division (OHD) issued its first report which described the monitoring and data collection system that was implemented under the law, and summarized the information collected on patients and physicians who had participated in the act through December 31, 1998. To better understand the impact of physician-assisted dying on the care of and decisions made by terminally ill Oregonians, OHD conducted two studies. Each study compared the characteristics of physician-assisted dying participants with a sample of Oregon patients and physicians who did not participate in the Death with Dignity Act. In addition to OHD's report, the results were also published in the *New England Journal of Medicine* ("Legalized physician-assisted suicide in Oregon: The first year's experience") on February 18, 1999. A summary of the results contained in OHD's report is set out below.

Twenty-three (23) persons who received legal prescriptions for lethal medications in 1998 were reported to OHD. Of these 23 persons, fifteen (15) died after taking their lethal medications, six died from their underlying illnesses, and two were alive as of January 1, 1999 (apparently because they elected not to use the medications). The median age of the 21 prescription recipients was 69 years and ranged from the third to the tenth decade of life. All 21 patients were white, and 11 (52%) lived in the Portland Tri-county area. Of the 21 recipients, 20 had been residents of Oregon for longer than 6 months when they received their prescriptions. One patient had moved to Oregon 4 months prior to death to be cared for by family members and not because of legally assisted suicide. Four of the twenty-one prescription recipients had a psychiatric or psychological consultation and all patients were ultimately determined to be capable in the context of the Death with Dignity Act. All physician reports were in full compliance with the law. (OHD Report at p. 4.)

Among the reported findings from OHD's 1998 data collection and comparison studies are:

- ☞ Physician-assisted dying accounted for approximately 5 of every 10,000 deaths in Oregon in 1998.
- ☞ Patients who chose physician-assisted dying in 1998 were similar to all Oregonians who died of similar underlying illnesses with respect to age, race, sex, and Portland residence.
- ☞ Patients who chose physician-assisted dying were not disproportionately poor (as measured by Medicaid status), less educated, lacking in insurance coverage, or lacking in access to hospice

care.

✍️ Fear of intractable pain and concern about the financial impact of their illnesses were not disproportionately associated with the decision by those who chose physician-assisted dying.

✍️ The choice of physician-assisted dying was most strongly associated with concerns about loss of autonomy and personal control over bodily functions.

✍️ In 1998, many hospitals and physicians in Oregon were unable or unwilling to participate in physician-assisted dying.

✍️ Physicians who wrote prescriptions for lethal medications for patients who chose physician-assisted dying represented a wide range of specialties, ages, and years in practice. (OHD Report at pp. 7-8.)

OHD's report notes that considerable debate has focused on the characteristics of terminally ill patients who choose physician-assisted dying. "Some feared that patients who were minorities, poor, or uneducated would more likely be coerced into choosing physician-assisted suicide. Others feared that terminally ill persons would feel pressured, either internally or through external forces (e.g., family members or health care systems) to choose physician-assisted suicide because of the financial impact of their illnesses. To date, the Oregonians who have chose physician-assisted suicide have not had these characteristics. ... No person who chose physician-assisted suicide expressed a concern to their physician about the financial impact of their illness. The proportion of patients with private insurance and Medicaid were similar among those who chose physician-assisted suicide and among controls. This provides some evidence that socioeconomic status was not associated with the decision to take lethal medication." (OHD Report at p. 8.)

The study also noted that end of life care has made great strides in Oregon in recent years. "Oregon ranks third, nationally, in the rate of hospice admissions. More than two-thirds of the patients who chose physician-assisted suicide were enrolled in a hospice program when they died. ... To date, lack of access to hospice care has not been associated with the decision to take lethal medications. Fear of intractable pain was also an end of life care issue not associated with physician-assisted suicide." (*Id.*)

"The primary factor distinguishing persons in Oregon selecting physician-assisted suicide is related to the importance of autonomy and personal control. Patients who chose physician-assisted suicide were seven times more likely to be concerned about loss of autonomy and nine times more likely to be concerned about loss of control of bodily functions than control patients. ... Many prescribing physicians reported that their patients' decision to request a lethal prescription was consistent with a long-standing philosophy about controlling the manner in which they died. The fact that 79% of persons who chose physician-assisted suicide did not wait until they were bedridden to take their lethal medication provides further evidence that controlling the manner and time of death were important issues to these patients. Thus, in Oregon the decision to request and use a prescription for lethal medications in 1998 appears to be more associated with attitudes about autonomy and dying, and less with fears about intractable pain or financial loss." (*Id.*, at pp. 8-9, emphasis added.)

OHD's report also noted that there are several limitations that are important to consider when interpreting these results. First, the number of patients who chose physician-assisted suicide in 1998 was relatively small, which limits the ability to detect small differences between the characteristics of persons who chose physician-assisted suicide and control patients. Second, the possibility of physician bias must be considered. To maintain consistency in data collection and to protect the privacy of the patient and the prescribing physician, interview data were only collected from prescribing physicians. All physician interviews were conducted after the patients' death. OHD did not interview or collect any information from patients prior to their death, nor did they collect data from patients' families at any time. Finally, the Death with Dignity Act requires OHD to both collect data on patients and physicians who participate in the act, and to report any noncompliance with the law to the Oregon Board of Medical Examiners for further investigation. Because of this dual obligation, OHD was unable to detect or collect data on issues of noncompliance with any accuracy. According to OHD, a 1995 anonymous survey of Oregon physicians found that 7% of surveyed physicians had provided prescriptions for lethal medications to patients prior to legalization. OHD states that it is unaware if covert physician-assisted suicide continued to be practiced in Oregon in 1998. (OHD Report at pp. 3, 9.)

The Netherlands. Unlike Oregon, the Netherlands, which has universal health care coverage, does not have any legislation regulating physician-assisted dying or euthanasia. Despite this lack of legal authority, approximately 3100 cases of euthanasia and 550 cases of physician-assisted dying occur annually in the Netherlands, representing 2.3% and 0.4%, respectively, of all deaths. (Ezekiel Emanuel & Margaret Battin, "What Are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?" 339 *New England Journal of Medicine* 167-172, July 16, 1998.) There are an additional 1000 cases (0.7%) in which euthanasia is performed without the patient's explicit current consent. Such cases are neither sanctioned in the Netherlands, nor, of course, are they permitted by this bill or any of the other current proposals for legalization of physician-assisted dying in the United States. About 80% of deaths by physician-assisted dying or euthanasia in the Netherlands involve patients with cancer, representing 6% of all deaths from cancer. Interestingly, more than 90% of Dutch patients who died as a result of physician-assisted dying or euthanasia at their own explicit request had their lives shortened by 4 weeks or less, with an average life reduction of less than 3.3 weeks. (*Id.*)

Social Backdrop. Numerous national polls have asked Americans their views on a terminally ill patient's right to request physician-assisted dying. Three polling groups – the Gallup Organization, the Harris Poll, and the Roper Organization - have asked this question, with slightly different wording a total of nine times between 1947 and 1996. According to information provided by the author, the results consistently show support for physician-assisted dying.

In the first poll taken in 1947, 37% of those polled were in support, while 54% opposed. In all of the other polls taken, Americans supported the choice of physician-assisted dying for terminally ill patients with safeguards. During the last decade, the support has grown to 75% in 1996, with the poll results in 1990 at 65% support, 1993 at 73%, and 1994 at 70%.

In California, a Fairbanks poll of 750 Californians was reported at a conference hosted by the Death with Dignity National Center in San Francisco on November 13, 1998. This recent poll found that 71% agreed that a person with a terminal illness should be allowed by law to choose physician-assisted dying; 22% disagreed, with only 7% undecided. According to the author, the most striking numbers in this poll were

in the strongly agree (52%) and strongly disagree (15%) categories. Pollsters interpret this to show that the public has strong feelings about the issue combined with a small number (7%) of undecided. These polls consistently show the public is knowledgeable and decisive about this issue.

#### Medical Backdrop:

The Impact Of Medical Technology On Dying. The debate over whether terminally ill patients should have a right to reject medical treatment or to receive aid from their physicians in hastening their death has taken on a new prominence as a result of recent developments in medical technology. During the last century, Americans died from a host of illnesses and infirmities that killed their victims quickly but today are almost never fatal in this nation – scarlet fever, cholera, measles, diarrhea, influenza, pneumonia and gastritis, to name a few. As a result of modern medical technology, most Americans now die from slow acting ailments such as heart disease, cancer, and cerebrovascular disease. Many of these individuals are increasingly likely to die in institutions as a result of these chronic illnesses. The issue of pain relief therefore becomes an increasingly important issue in the Death with Dignity debate.

A Brief Comparison of Palliative Care Options. “Palliative” means “relieving or soothing the symptoms of a disease or disorder without affecting a cure.” (The American Heritage College Dictionary, 3d ed., 1997.) Palliative care is generally understood as the standard of care when terminally ill patients find that the burdens of continued life-prolonging treatment outweigh the benefits. However, even the highest quality palliative care can fail or become unacceptable for some patients, a small portion of whom request help in hastening death. According to some studies, between 10% and 50% of patients in programs devoted to palliative care still report significant pain 1 week before death. Patients who seek the “Death with Dignity” option also request a hastened death not simply because of unrelieved pain, but because of a wide variety of unrelieved physical symptoms in combination with loss of meaning, dignity, and independence.

There are four practices which are considered to be palliative options of last resort: voluntarily stopping eating and drinking (VSED), terminal sedation (TS), physician-assisted dying (PAD), and voluntary active euthanasia (VAE). (Timothy E. Quill, MD, et al., “Palliative Options of Last Resort,” 278 *Journal of the American Medical Assn.* at 2099 (Dec. 17, 1997)(“Palliative Options”).) With VSED, a patient who is otherwise physically capable of taking nourishment makes an active decision to discontinue all oral intake and then is gradually “allowed to die,” primarily of dehydration or some intervening complication. (Palliative Options, at p. 2099.) The main disadvantages of VSED are reportedly that it may last for weeks and may initially increase suffering because the patient may experience a high degree of thirst and hunger. In addition, some patients, family members, physicians, or nurses find the notion of “dehydrating” or “starving” a patient to death to be morally repugnant. Patients are also likely to lose mental clarity toward the end of this process, which may undermine their sense of personal integrity or raise questions about whether the action remains voluntary. (Palliative Options, at p. 2100.) No data is currently available about how frequently such decisions are made or how acceptable they are to patients, families, physicians or nurses. (*Id.*)

With TS (terminal sedation), the suffering patient is sedated to unconsciousness, usually through ongoing administration of barbiturates or benzodiazepines. The patient then dies of dehydration, starvation, or some other intervening complication, as all life-sustaining interventions are withheld. Although death is

inevitable, it usually does not take place for days or even weeks, depending on clinical circumstances. Because patients are deeply sedated during this terminal period, they are believed to be free of suffering. Terminal sedation is already openly practiced by some palliative care and hospice groups in cases of unrelieved suffering with a reported frequency from 0% to 44% of cases. In addition, many proponents believe it is appropriate to use TS with patients who lack decision-making capacity but appear to be suffering intolerably, provided that the patient suffering is extreme and otherwise unrelievable, and the patient's surrogate decisionmaker or family agrees. (Palliative Options, at p. 2100.)

Nonetheless, TS remains controversial. Like VAE, the final actors are the *clinicians*, not the patient. Proponents of AB 1592 note that terminal sedation can be carried out without explicit discussions with alert patients who appear to be suffering intolerably or even against their wishes. In addition, some competent, terminally ill patients reject TS. They believe that their dignity would be violated if they had to remain unconscious for a prolonged time before they die, or that their families would suffer unnecessarily while waiting for them to die.

With PAD (physician-assisted dying), the physician provides the means, usually a prescription of a large dose of barbiturates, by which a patient can end his or her life. Although the physician is morally responsible for this assistance, the *patient* has to carry out the final act. Because patients have to ingest the drug by their own hand, their action is likely to be voluntary. Physicians report being more comfortable with PAD than VAE, presumably because their participation is indirect. Several studies have documented a secret practice of PAD in the United States. In Washington State, 12% of physicians responding to a survey had received genuine requests for PAD within the year studied. Twenty-four percent of requests were acceded to, and over half of those patients died as a result. An Oregon study showed similar results. As noted above, Oregon is the only state where PAD is legal. Thus, PAD, in other states, is usually conducted covertly, without consultation, guidelines, or documentation. (Palliative Options, at pp. 2100-2101.)

With VAE (voluntary active euthanasia), the physician not only provides the means, but commits the final act by administering a lethal injection at the patient's request. For patients who are prepared to die because their suffering is intolerable, VAE has the advantages of being quick and effective. Patients need not have manual dexterity, the ability to swallow, or an intact gastrointestinal system. Physicians can ensure the patient's competence and voluntariness at the time of the act, support the family, and respond to complications. On the other hand, VAE explicitly and directly conflicts with the traditional medical prohibitions against intentionally causing death. Furthermore, VAE could be conducted without explicit patient consent. If abused, VAE could arguably be used on patients who appear to be suffering severely or posing extreme burdens to the physician, their family, or society, but who have lost the mental capacity to make informed decisions. (Palliative Options, at p. 2101.)

Summary Of Principal Arguments In the Death with Dignity Debate. With the legal, social and medical background considered, this analysis will now turn to a review of some of the principal arguments for and against this measure.

Are There Sufficient Safeguards? According to proponents, AB 1592 requires physicians to do two things that are extraordinary given the usual practice issues associated with medical transactions between doctors and patients. First, the bill requires two physicians (and a mental health professional if



necessary) to establish that a number of careful safeguards have been met and meticulously documented. The required forms must be charted and filed with the Department of Health Services (DHS) upon the physician writing the prescription. Second, they note that physicians must be very careful with this process, for they know that these forms will be audited and scrutinized by the DHS because the department is required to submit an annual statistical report on the law.

Opponents counter these "tough safeguards" arguments by noting concerns that the doctor doesn't really need to know or have a long-standing relationship with the patient and that the second physician will tend to validate his or her colleague. They also argue that the family notice requirement is too lax.

Potential for Abuse: The "Slippery Slope." Opponents argue that in the United States and in California, where there is no universal entitlement to health care, a policy of physician-assisted suicide has great potential for abuse. They worry that responding to subtle yet powerful social and economic pressures, the active killing of terminally-ill patients might extend to non-terminally ill or socially devalued persons such as the elderly, chronically-ill, or people with disabilities, where the "right to die" may become a "duty to die." According to opponents, fully informed and voluntary decision making may be jeopardized by not so subtle coercion by health professionals, family, third-party payors, and society. Opponents also argue the potential for abuse is heightened in a time of declining health care resources, where competition for those resources occurs between old and young, or between the chronically and acutely ill.

Proponents respond by noting that AB 1592 is modeled after Oregon's Death with Dignity Act, and that the report on the first year's experience in Oregon does not support those fears of the slippery slope. The 23 patients who chose a hastened death under the Oregon law last year were all terminally ill, with terminal cancer, lung or heart disease. All of these patients were dying. There was no indication that disabled or frail, elderly patients were given access to physician-assisted dying. It was strictly utilized only by patients already in the dying process. The *New York Times* reported that the Oregon study showed that Oregon's Death with Dignity Act "has not led to abuses... or a widespread rush among the sick or suffering to move to Oregon for the right to be put to death, as many critics of the law had contended." (*New York Times*, "Oregon Reporting 15 Deaths in Year Under Suicide Law: Officials See No Abuses" Feb. 18, 1999.)

Instead of creating a slippery slope, proponents contend AB 1592 would shed light on current practice. Doctors who are currently assisting deaths in California are doing so secretly, and are thus totally unregulated and acting without any safeguards in place. AB 1592 would regulate the practice of physician aid in dying, and would prevent "slippery slope" cases, such as assisted deaths of incompetent or non-terminal patients, from taking place.

Proponents also argue experience has shown no "slippery slope" when it comes to existing California laws relating to patient requests for a hastened death. Advance directives, such as a Durable Power of Attorney for Health Care, have been part of California law for over a decade, allowing a patient to request withholding or withdrawal of all life support. Proponents state there are no reports of abuse of this law by the undue influence of family members, physicians, or others. According to proponents, the current opponents of physician-assisted dying also opposed the passage of advance directives for the same reasons. They now affirm the value of those laws.

Opponents counter such statements of reassurance, however. They note there is no precedent in this state for this type of physician-assisted death. They claim that there is a profound and time-honored difference between killing and letting die – a difference that proponents would like to obscure. Opponents also state that the reason proponents find words like "killing" and "suicide" pejorative is because they view the killing of a terminally ill person as a different event than the killing of a fully functional one.

Problem Of Defining Terminal Illness. A number of opponents argue that the difficulty of determining that a person is "terminally ill," with any degree of accuracy, will also present a significant problem for justifying physician-assisted dying. Prognostication in medicine is a notoriously uncertain art. Whether a patient is considered "terminal" is quite often an arbitrary determination, and may or may not correlate with the degree of suffering the patient experiences. Doctors sometimes estimate their patients have only months to live, but they survive much longer. They also argue that diseases sometimes go into remission, new treatments appear, the diagnosis was wrong, or the prognosis was too pessimistic. According to some opponents, this bill will bring untimely death in all these circumstances.

Proponents contend the argument that sometimes it is difficult to determine if a patient is terminal is simply not good medicine and not good law. According to proponents, even in the briefs submitted to the U.S. Supreme Court, no one challenged the notion that doctors can distinguish the differences between terminally ill and chronically ill patients. Further, practitioners in specialties such as hospice and palliative care recognize the specific symptomatology of terminally ill and dying patients. In specialty practices such as gerontology and oncology, doctors treat a high percentage of terminally ill patients.

Proponents acknowledge that medical diagnosis is not 100% certain, nor will it ever be. However, they note that doctors are called upon every day to make these diagnoses, which are relied upon routinely in cases involving termination of life-support. Indeed, in those cases, life-sustaining treatment can be terminated on the authority of a family member or other patient surrogates even when the patient is incompetent. According to proponents, no evidence has been introduced that abuses are occurring in such cases, nor is there any reason to believe the same types of determinations by physicians would be any more fallible in the context of physician-assisted dying, which requires the active involvement and consent of the patient. Nevertheless, opponents of AB 1592 worry deeply that since prognostication in medicine is so uncertain, needless deaths will undoubtedly occur.

Frail Elderly: Opponents argue that elderly patients in pain could easily be coerced into physician-assisted dying. Proponents state that the concerns regarding the frail elderly that are raised by opponents are not well-founded. According to Dr. Locatell, a geriatrician who specializes in palliative care, elderly patients are not any less competent than others to determine their medical care. Proponents acknowledge that there are many elderly who suffer from dementia, depression or other mental disabilities, but these patients are not eligible for physician-assisted dying under this bill because they would not satisfy the bill's strict competency requirements.

People With Disabilities. Opponents of AB 1592 argue strongly that the bill's apparent restriction to cases of terminal illness is hardly reassuring in view of the fact that many people with disabilities who have been identified as "terminal" go on to live full and meaningful lives for many years longer. They

note the Oregon report revealed that most of those who chose death did so not because of intractable pain but rather because they feared losing control of their bodily functions and autonomy over their lives. In other words, they feared becoming disabled. Opponents argue that if the law authorizes assisted suicide based on fear of disability, how can they believe the option won't be extended to those who already are living with disabilities.

Proponents counter by citing to a recent article by Anita Silvers, a noted scholar on people with disabilities, which found that there is "no statistical evidence nor experiential basis for suggesting that, as a group, people with disabilities are pathologically disposed to suicide. There was no reason to accept the claim that the judgment of individuals with disabilities are so incapacitated by the exclusion and isolation they face as to make them incompetent and incapable of self-determination." (Anita Silvers, "Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups," *Physician Assisted Suicide, Expanding the Debate*, at 133, 142 (1998).) Silvers continues that "despite acknowledging the systemic marginalization that people with disabilities endure, it seems wrong to think that having any kind of disability means being cognitively or psychologically disabled by society. To do so is to equate being disabled in any way with being globally debilitated." (*Id.*) She also argues that construing people with disabilities as a class so vulnerable as to warrant substituting the state's protective judgment for their self-determination so misperceives their competence as to exacerbate the bias which already contracts their opportunity for social participation." (*Id.*, at pp. 145-46.)

Finally, in response to the argument that distrust of doctors already exists among people with disabilities, and will be further eroded by legalizing physician-assisted dying, proponents quote an editorial from Dr. Marcia Angell in the *New England Journal of Medicine*: "Contrary to the frequent assertion that permitting physician assisted suicide would lead patients to distrust their doctors, I believe distrust is more likely to arise from uncertainty about whether or not a doctor will honor a patient's wishes." (Dr. Angell was quoted in "Ethics and the Medical Ambivalence towards Death," by Daniel Callahan, *Human Medicine*, Vol. 10, No. 3 (July 1994) at p. 183.)

Would Physician-Assisted Dying Further Disability Discrimination? It should come as no surprise that people with disabilities, like the public at large, have differing views on the subject of physician-assisted dying. Some members of the disability community have been highly vocal in opposing the right to physician-assisted dying, based on the long and sordid history of discrimination and oppression against people with disabilities. Others believe that the right to hasten the end of their lives with the assistance of their physicians is a natural extension of their efforts to maintain autonomy in the face of such discrimination.

Debate Between Two Prominent Disability Rights Advocates. In a February 1997 conference call, Paul Longmore, an associate professor at San Francisco State University, and one of the disability community's most outspoken opponents of legalized physician-assisted dying, debated Andrew Batavia of Miami Beach, Florida, a well-known attorney and health and disability policy expert who favors legalization. The following selected excerpts from their discussion, which was published in *New Mobility Magazine* ("Death Do Us Part," April 1997), are representative of the deep ethical and philosophical split within the physical disability community on this issue. The discussion began with a question: Can a request by a disabled person for a physician's assistance in dying be seen as a rational and uncoerced

choice?

*Paul Longmore:* Historically, when people with disabilities have wanted a physician's help in ending their lives, courts have automatically assumed that first, they were acting in response to their disability alone and second, it was a reasonable thing to want to die. Whereas, for someone who is not disabled, the automatic response is to try to help the person and solve the problems. This happens to people with disabilities even when it's made clear that there are all sorts of societal factors that have brought the person to this point.

*Andrew Batavia:* I understand that people with disabilities have always been devalued and we need to rectify that. Certainly, we need to educate the public and the medical community. But I feel that the individual should be able to make the decision. In the context of the Supreme Court case being considered now, we're talking about the right of competent, terminally ill individuals to end their lives. These people are suffering, they're in the last few months of their lives, and there's no reason that the state should interfere. Their decisions have to be respected as rational.

*PL:* ...I find it ironic that, on the one hand, proponents of legalization are arguing that doctors can't be trusted because they too often want to compel people to live. The experience of people with disabilities is directly opposite to that. And then they want doctors to both determine eligibility and carry it out – the same doctors who are currently under tremendous pressure from the managed care revolution to ration health care to people who are regarded as costly.

*AB:* I have major problems with this notion of societal oppression and how that somehow precludes an individual from making a rational choice. The fact is that there are a multitude of ways in which our society doesn't fully meet the needs of people with disabilities, but I find it extremely dangerous to say that, for that reason, disabled people shouldn't be able to make fundamental choices about their lives. If a state tells me I can't end my life if I'm terminally ill, then the state is oppressing me.

*PL:* It's one thing to make fundamental choices; it's another thing to have the society that's oppressing us set up mechanisms to facilitate our suicides. Any society that would guarantee assistance in committing suicide by an oppressed person is simply indicating just how oppressive and hypocritical it is.

#### Recent Polling Data Finds Majority Of People With Disabilities Support Physician-Assisted Dying.

According to a recent public opinion poll, 66% of people with disabilities support the right to physician-assisted suicide, as compared with 70% of the general population. (Lou Harris and Associates, Harris Poll No. 9, Table 105 (1995).) This result is corroborated by a recent study which found that 63% of people with AIDS support this right, and 55% actually have considered this option for themselves. (William Breitbart, et al., "Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients," 153 *Am. J. Psych.* 238 (1996).) Another study found that 90% of people with AIDS support the right. (Brett Tindall, et al., "Attitudes to Euthanasia and Assisted Suicide in a Group of Homosexual Men with Advanced HIV Disease," 6 *J. Acquir. Immune Defic. Syndr.* 1069 (1993).)

One Person's Experience. In a 1994 interview, John Foss, a long-time Board member of Americans for Death with Dignity, was asked why he would choose to end life a moment sooner than it might naturally

end. Foss explained:

"Quality of life for me is living to the best of my ability in a pain-free environment if at all possible. I demand a very rigorous and a very healthy quality of life. But when that quality is deteriorating and I have no control over it, at that time is when I have to make my decisions. I am the only one who should be the judge and the jury as to what degree of quality I have. I don't think a doctor, family member or anybody else should have that right."

In response to a question regarding whether choosing physician aid in dying is morally wrong, Foss said:

"Walk in my shoes before you make your judgments. Live the life that I've got to live with this disease, and then you have a right to tell me how I should or should not feel and act. As for morality, if it falls in the scope or parameters of my determination of morality that I live by, then it's satisfactory to me, and if it doesn't fall in that scope for you or anybody else, that's your problem"

John Foss died peacefully on June 12, 1994, after a years-long battle with AIDS.

Effects Of Lack Of Access To Hospice Care. The California State Hospice Association (CSHA) supports public policy and legislation designed to provide the highest quality of medical and palliative care to people at the end of life. CHSA and a number of its affiliates believe that legalizing physician-assisted dying is not in the best interests of the dying, their families or society, and they do not support such legislation. Hospice brings a tradition of stewardship of resources, interdisciplinary team management, patient-family advocacy and ethical decision-making to the management of chronic, catastrophic and terminal illness. With expertise and compassion, hospice addresses the physical, emotional and spiritual needs of people with life-threatening illnesses. With hospice's support, patients and families have rediscovered a comforting sense of community in what is a difficult and stressful time. However, CHSA acknowledges that at least 5% of patients suffer from pain which cannot be alleviated even with the best pain management techniques.

CHSA shares the sentiments expressed by a founder of the modern hospice movement, Dame Cicely Saunders, who said, "You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die." The organization believes that the legalization of physician-assisted dying, however well intentioned, may open the door for abuses of the rights and dignity of dying people. Laws are symbols of what society values. According to CSHA, measures such as AB 1592 can cause us to dehumanize the process of dying and, as a consequence, ultimately devalue life.

Proponents respond that, to date, lack of access to hospice care has not been associated with the decision to choose physician-assisted dying. (OHD Report, p. 8.) Since Oregon implemented physician-assisted dying, hospice enrollment has actually increased. Oregon now ranks third nationally in the rate of hospice admissions. (OHD report, p. 8.) "Oregon has shown increased attention to comfort measures in two ways. First, the rate of admission to hospice grew 20% in 1995 and continues to increase... Second, Oregon

currently leads the United States in the medical use of morphine... Oregon is fortunate to have fewer impediments to appropriate prescribing practices than some other states." (Susan Tolle, MD, "Care of the Dying: Clinical and Financial Lessons from the Oregon Experience," *Annals of Internal Medicine*, Volume 128, No. 7, April 1, 1998, p. 568.) David Mayo, a philosopher with the University of Minnesota's Center for Bioethics stated: "The great irony is that they (doctors) didn't give a damn about palliative care until the Oregon initiative passed." (Mark O'Keefe, "A New Way of Dying," *Oregonian*, Sept. 28, 1997.)

According to the Oregon report, the rate of hospice enrollment for the case patients who chose physician-assisted dying (71%) was almost identical to the rate for the matched control group (74%). And of the four Oregon patients who chose physician-assisted dying but were not enrolled in hospice, three of them had repeatedly refused enrollment offers to hospice. (OHD Report, p. 8) Access to hospice does not seem to be a factor among those choosing physician-assisted dying. According to the Oregon report, physician-assisted dying "was not disproportionately chosen by terminally ill patients who were poor, .. uninsured, fearful of the financial consequences of their illnesses, or who lacked end of life care."

Even under a perfect system of health care, proponents contend there will still be a small group of dying patients who choose to end their suffering. It is for those few patients who request it that the option of a hastened death needs to be available. For example, roughly 80% of cancer pain responds to pharmacological management. This leaves roughly 20% whose pain cannot be managed. (Oxford Textbook of Palliative Medicine, 2nd Edition, 1998) Indeed, the American Academy of Hospice and Palliative Medicine (AAHPM) recognizes that "even given the best that palliative care can offer, not all severe suffering can be alleviated." (AAHPM, Position Statement on Comprehensive End-of-Life Care and Physician-Assisted Suicide, p. 2, June 25, 1997.)

Link Between High Cost Of Health Care And Physician-Assisted Dying? A number of opponents have argued that there are potential cost savings from legalizing physician-assisted dying, and that these savings may improperly influence decision making by health care institutions, families and terminally ill patients. For example, one opponent argues that "[l]egalizing physician-assisted suicide would allow health plans, insurance companies and public programs like Medicare and Medicaid to appear 'compassionate' while they cut back or eliminate coverage for the health and support services that can make for a good quality of life even in the face of significant disability and illness. For that reason, legalization is likely to reduce access to the very things that might give a seriously ill or disabled person a desire to continue living." (Laura Remson Mitchell, "Red Flag on the Slippery Slope," *LA Times*, p. B9, Feb. 2, 1998.)

Proponents counter this argument by pointing to a recent study which found that the cost savings can be predicted to be very small – less than 0.1 percent of both total health care spending in the United States and an individual managed-care plan's budget. (Ezekiel Emanuel & Margaret Battin, "What Are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?" *The New England Journal of Medicine*, Vol. 339, No. 3, July 16, 1998.)

Terminal Sedation vs. Physician-Assisted Dying. In the Washington v. Glucksberg and Vacco v. Quill cases discussed above, three concurring Supreme Court justices endorsed the practice of terminal sedation (Glucksberg, supra, 117 S.Ct. at 2302), and the five-justice majority expressly rejected the claim

that terminal sedation "is covert physician-assisted suicide." (*Id.*, at 2298.) In a recent article published in the *New England Journal of Medicine*, David Orentlicher, M.D., J.D., of the Indiana University School of Law, compared the practices of terminal sedation (TS) and physician-assisted dying (PAD), and concluded that the Court undermined the distinction between the withdrawal of life-sustaining treatment and assisted-suicide or euthanasia when it endorsed TS. (D. Orentlicher, "The Supreme Court and Physician-Assisted Suicide: Rejecting Assisted Suicide but Embracing Euthanasia," 337 *New England Journal of Medicine* 1236 (Oct. 23, 1997) ("Orentlicher").)

Orentlicher presents the justification for TS as "the underlying disease creates the need for the sedation by causing the patient to ask for palliation." This logic applies equally to PAD since "it is the underlying disease that causes the patient to ask for a life-ending drug". Orentlicher accurately describes the physician action in TS as follows: "[T]he sedated patient often dies from the combination of two intentional acts by the physician—the induction of stupor or unconsciousness and the withholding of food and water. Without these two acts, the patient would live longer before succumbing to illness." He goes on to describe the similarities of conditions between a patient already in a coma, where life support and food and hydration are withdrawn and during TS: "In such cases, it is the physician created state of diminished consciousness that render the patient unable to eat, not the patient's underlying disease." (Orentlicher, *supra*, at p. 1237)

Orentlicher also points out that if TS was really not a means of medically approved PAD, then doctors would not withhold food and hydration: "We cannot justify the withdrawal of food and water during TS, for that step does nothing to relieve the patient's suffering but only serves to bring about the patient's death." (*Id.*, at 1237.) In addition, Orentlicher notes that when a patient chooses TS, "the patient also chooses a treatment that is uniformly fatal. If intent is not relevant to TS, it is also not relevant to PAD." (*Id.*, at 1238.)

Conclusion. Regardless of one's views of the merits of the bill, this legislation addresses head-on one of the most intimate and personal decisions that an individual can make. Judge Stephen Reinhardt's eloquent statement regarding the profound nature of the issues raised in the recent legal challenge to the State of Washington's ban on assisted-suicide applies with equal force to this legislation:

"This [legislation] raises an extraordinarily important and difficult issue. It compels us to address questions to which there are no easy or simple answers, at law or otherwise. It requires us to confront the most basic of concerns – the mortality of self and loved ones – and to balance the interest in preserving human life against the desire to die peacefully and with dignity. People of good will can and do passionately disagree about the proper result[.] ... [T]he controversy before us [is] a controversy that may touch more people more profoundly than any other issue the courts [or the Legislature] will face in the foreseeable future." (*Compassion in Dying v. Washington* (9<sup>th</sup> Cir. 1995) 79 F.3d 790, 793.)

Prior Legislation. AB 1080 (Martinez) and AB 1310 (Mazzoni) of 1995, which were also modeled after the Oregon Death with Dignity Act, were not brought to a hearing in the Assembly Judiciary Committee.

Proposition 161, which would have allowed either administration of lethal medications by the physician or self-administration of the medications by the patient, was rejected by the voters by a 46% to 54% margin at the General Election held November 3, 1992.

REGISTERED SUPPORT / OPPOSITION:

Support

Americans for Death with Dignity (sponsor)  
American Civil Liberties Union  
Congress of California Seniors  
Democrats for Action  
Friends of Dying Patients  
Grief Support Training Institute  
Older Women's League of California  
Over 1200 individuals who wrote the Committee in support

Opposition

American Nurses Association\California  
California Association of Catholic Hospitals  
California Association for Health Services at Home  
California Catholic Conference of Bishops  
California Medical Association  
California Nurses Association  
California Right to Life Committee, Inc.  
California Society of Anesthesiologists  
California State Hospice Association  
Church of St. Anne, Council of Stewards  
Committee on Moral Concerns  
Crusade for Life, Inc.  
Elizabeth Hospice (serving North San Diego and Southern Riverside counties)  
Hoffman Hospice of the Valley  
Hospice of Napa Valley  
Hospice of the Owens Valley  
Hospice Services of Lake County  
Long Beach Area Republican Assembly  
Phoenix Hospice  
Pro-Life Political Action Committee of Orange County  
Scholl Institute of Bioethics  
Snowline Hospice of El Dorado County  
St. Joseph Health System, Southern California Region  
Sutter Hospital, Roseville  
Trinity Care Hospice  
Tulare County Chapter, California Pro-Life Council  
Over 30 individuals who wrote the Committee in opposition



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